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"To manage a complex dependency: the experience of care giving after a fall"

Running head: Caring after a fall

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ABSTRACT

Aim: To understand the experience of family members of an older relative who has had a fall which required medical attention.

Background: There is abundant bibliography in caregiving, but little is known about the problems faced by caregivers and how family members cope when their older relative has a fall.

Design: Qualitative study that used a symbolic interactionism perspective.

Methods: Twenty-two people with older relatives who had had a fall and contacted health services in Spain, participated in the study. Data was obtained via written accounts, focus groups and semi-structured interviews between February 2014 - December 2015. Analysis was guided by grounded theory procedures.

Results: With the fall, dependency becomes a complex issue for the family. To manage a complex dependency is the core issue that emerges from the data analysis. It depicts family efforts to assist

their relative in gaining autonomy after a fall, in the best conditions they can provide. They do this with little guidance and support from health care professionals.

Conclusions: Guides and protocols for the care of a fragile older person, particularly after a fall, should not only include care but also support to caregivers. Health professionals and especially nurses need to be aware and respond to the family caregivers needs after a fall. To the fall prevention initiatives already in place, it must be added that those who support family members to cope with the care of an older person who has had a fall.

Key words: caregiving, focus groups, nursing home care, older people, falls, qualitative approaches

Why is this research needed?

- Falls are the most serious and frequent accident older people have in their homes.
- In fall prevention the family play a crucial role but the information they receive, and educational needs are not met**.**
- Despite the abundant bibliography about caregiving, little is known about the problems caregivers face and how they cope when their older relative has a fall.

What are the key findings?

- A complex dependency is the challenge that family caregivers face after their relatives fall.
- Preparing the transition to home, making adjustments and meeting the shortcomings of the health system are tasks caregivers' have to deal with, in the highly complex situation of after a fall.

- Although caregivers felt well treated by health professionals, they did not feel supported nor informed by them about how to handle their relative's complex dependency.

How should the findings be used to influence policy/practice/research/education?

- Guides and protocols for the care of the fragile older people, particularly after a fall, should include care and support to caregivers.
- Nurses need to be aware and respond to family needs after a fall and must be proactive in preparing them for the care of the older relative.
- To the initiatives on fall prevention already in place, it must be added those that support family members to cope with the care of an older relative after a fall.

INTRODUCTION

Falls are the most serious and frequent accidents that older people have in their homes and they are the main reason for hospital admissions (EIP, 2012). To reduce the number of older people falling is a health target in many countries and a priority in the European Union (EIP, 2012). The strategies with the most potential to prevent falls are modifying risk factors and changing the behaviour of the older person living in the community (Todd & Skelton, 2004). Fall prevention interventions must be multiple, multi factorial (Gillespie et al., 2012) and delivered by a multi-professional team (WHO, 2007) in collaboration with the older person and their significant others (Lampiasi & Jacobs, 2010).

Injuries caused by falls are frequent and serious (Holleran, 2015), in Europe they are the cause of 29% of fatal injuries of older people, mostly of women (EuroSafe, 2014). Falls are a risk factor themselves, as the person who has fallen is prone to fall again within a year (Todd & Skelton, 2004), falls put a strain on the family. It has been found that the burden of care is greater for family

caregivers (Magio et al., 2010), caregiving alters their lives (Dow, Meyer, Moore & Hill, 2013) and affects their quality of life (Roth, Perkins, Wadley, Temple & Haley, 2009).

The moral obligation to care for a relative is a universal issue in family care (Wallhagen & Yamamoto-Mitani, 2006); it can be considered as a life situation where responsibilities are acquired as happens in marriage or with parenthood (Ayres, 2000). On average, 15% of people over 50 years of age provided care for a dependent relative or friend across countries in the Organization for Economic and Cooperation Development (OECD, 2015). Spain has the highest rate of intensive informal caregiving in Europe (Verbakel et al., 2017).

The Spanish National Health System provides universal and equitable health services coverage. Long term care (LTC) has broad coverage as the 2006 Act established it as a universal right but has relatively low degree of social protection (Rodríguez Cabrero & Marbán Gallego, 2013). The system favours service provision over cash benefits being the most important home care services, day centres, tele-care at home and nursing homes. However, less than 10% of over 65s are receiving LTC in institutions or at home (Muir, 2017). Home adaptations and assistive devices entitlement are needs tested. The Spanish caregiving structure still reflects a Mediterranean culture where women are mainly the providers of family welfare (IMSERSO, 2011). Paradoxically, in those countries where the family is primarily responsible for the care of the older person, few resources are available to support families (Glendinning et al., 2009). A shortage of this support contributes to the deterioration of caregivers' well-being (Ruppanner & Bostean, 2014).

Background

To care for someone at home is a complex activity; it requires increasingly sophisticated knowledge and skills (Rallison & Raffion-Bouchal, 2013). Research studies on the burden of care have tended to depict caregivers as needing support and resources; however, they also develop successful ways to care for a dependent relative and mobilize resources for caregiving (Kita & Ito 2013; Teitelman & Watts, 2009). Caregivers provide vital support for their sick relatives and have an active role in their recovery process (Ägard, Egerod, Tonnesen & Lomborg, 2015).

In fall prevention the family play a crucial role by encouraging risk reduction strategies (Yardley et al., 2007), assisting with exercise activities (Suttanon, Said, Byrne & Dodd, 2012), developing strategies to prevent further falls (McIntyre & Reynolds 2012) and negotiating hazard reduction and risk-taking behaviours (Ward-Griffin et al., 2004). However, they learn to care by trial and error (McInteyre & Reynolds, 2012); several research studies have uncovered caregivers' needs for information and training (Araujo, Lage, Cabrita & Texeira 2015; McDermott, Hoffmann & Haines, 2013). Caregivers often feel down, ignored or left with a sense of mistrust from service providers (McIntyre & Reynolds, 2012). In situations of sudden dependency caregivers simply feel unprepared (Nahm et al., 2010).

Despite the abundant bibliography about caregiving, little is known about the problems caregivers face and how they cope when their older relative has a fall. After a fall, older people leave the hospital without completing their rehabilitation, without being completely autonomous in their mobility and in their everyday activities (Nahm et al., 2010).

THE STUDY

Aim

The aim of the study was to understand the experience of family members of an older relative who has had a fall which required medical attention.

Design

This study was part of a larger one into the area of health service research. It is a qualitative study that used initial coding, focused coding, analytical memos, diagramming and theoretical sampling, all grounded theory procedures useful to analyse data obtained in natural settings (Charmaz, 2014). It took the perspective of symbolic interactionism, which sees people as active agents engaged in problem-solving processes and furthermore shaping their world (Blumer 1969). The focus of analysis in interactionist studies is human action.

The study was developed over two stages. The preliminary stage was to familiarise researchers with the experience of participants; while the following stage, which contained the main study, was where the bulk of the collection and data analysis was done.

Sample/Participants

Participants were relatives of an older person that had had one or more falls in the community. Sampling was initially purposeful and snowball (Morse, 1989); during data analysis it was theoretical (Charmaz, 2014) here, the emergence of variations in the issues discussed in focus groups and interviews by participants, was favoured. The criteria to select participants were relatives of an older person who had had one or more falls with a suspected injury and had contacted health services. Relatives that were not directly involved in the care of the older person and people under 65 years who had fallen were excluded. Participants were identified via hospital records and recruited with

the help of nurses from a health department in a province of Spain. Twenty-two relatives participated in the study; table 1 shows their socio-demographic characteristics and table 2 those of their older relatives.

Data Collection

Data were obtained from written accounts, focus groups (Carey & Asbury, 2012) and semi structured interviews (Swanson, 1986). It took place in two stages, between February 2014 - December 2015. Data collection ended with the saturation of categories.

Written accounts

Six written accounts were first obtained where participants described, based on a guide, their experiences with the health care services after their relative's fall (Box 1). These accounts familiarized researchers with participant's experience and contributed to the development of the focus groups guide. These participants took part in the focus groups afterwards.

Focus groups

Four focus groups were set up in a community centre. Seven to eight relatives of an older person who had had a fall were invited to participate in the groups, but not all were able to attend. As we considered the efforts that participants made to attend the group and the advantages of a small group (Carey & Asbury, 2012), we conducted groups of less than six participants. Focus groups lasted approximately two hours.

Meetings were conducted by a moderator with the help of two facilitators. Group discussions were based on a guide developed by the research team and revised for each focus group (Box 2). Revisions introduced issues, uncovered during analysis, into discussions and helped to check provisional categories and to saturate them.

Interviews

As attendance to the focus groups dropped and recruitment was increasingly difficult, we conducted five semi-structured interviews. Four of them took place in the participant's home and one in a community centre. Interviews facilitated the discussion of individual cases in detail and complementing data gathered during focus groups. They were especially useful for checking emerging analysis and for developing, through theoretical sampling, early categories. They were conducted by an experienced researcher (first author) and lasted approximately 45 minutes. The same guide used for the focus groups was used.

Focus groups and interviews were audio recorded and fully transcribed. To preserve participants' anonymity a code system was used to identify them. This code system is employed in this manuscript when data is cited.

Ethical considerations

Ethics approval for the studies was granted by the clinical ethics committee of the province's health department (Cod. 13/308 of 25-09-2013). Participants were fully informed about the study and signed their consent to participate. Focus group members were informed of the need to preserve the confidentiality of group discussions.

Data analysis

After entering data in the software Nvivo, it was analyzed by the first and third author. Analysis took place concurrently with data collection. Researchers interacted with data where insights, hunches and questions were evoked that served to guide data collection and analysis. Analysis began with the first author engaging in open coding of the participants' actions reported in focus groups and interview data. Through interactive and iterative processes of constant comparison, the first author sorted codes into categories that indicated participants' strategies to deal with the problem that arose after the fall of a relative. Next, written accounts were coded to contribute to the development of emerging categories. "Meeting the shortfalls in the system" was one of the first categories to emerge together with "on their own and without help".

As analyses proceeded, more categories emerged and the identification of the main concern for participants (Glaser, 1978) was "the relatives' dependency". The analysis then moved to focus on identifying characteristics of the problem or concern for participants. By comparing categories with bibliography, by refining them and making new links between them the category of "complex dependency" emerged. Lastly "to manage the complex dependency" emerged as the core category.

During the coding process analytical memos and diagrams were developed. Bibliography was consulted to promote researchers' theoretical sensitivity, which is the ability to recognize the relevance of data and to help in the development of categories (Charmaz, 2014; Glaser, 1968).

Rigour

Rigour was assured by obtaining data in an open way, by encouraging participation of all the members in focus groups, by keeping participants' experiences in the focus of analysis and by

member checking (Carey & Asbury, 2012; Charmaz, 2014; Lincoln & Guba, 1985). Analysis was inductive, seeking fit, relevance and workability (Glaser, 1978). Meetings among the researchers took place to discuss and agree on emerging findings and to guide data gathering; fit and relevance (Glaser, 1978) were the main criteria for reaching consensus. An independent scrutiny of the analysis and interpretation was carried out by the third author. A diary with methodological and reflexive notes was kept during the study (Lincoln & Guba, 1985).

FINDINGS

The study participants ranged in age from 35 years to over 70 years, most of them were adult offspring with extensive experience in caregiving. Despite women being the majority, the presence of male caregivers was significant in this study. We believed that this was because women have the greatest number of falls and those tend to cause fractures (Todd & Skelton, 2004; WHO, 2007).

Although most of the participants' older relatives were fragile when they fell, the fall made them dependent on their family for activities that they could previously do on their own. In some cases, the fall meant complete loss of their autonomous life. With the fall, dependency became a complex issue for the family; it found them unprepared and having to cope with complications and difficulties.

A complex dependency was identified as the main problem that family caregivers faced after their relative's fall. To manage a complex dependency was the core issue that emerged from data analysis. It depicted family efforts to assist their relative in gaining autonomy after a fall, in the best conditions they could provide. They did this with little guidance and support from health care professionals (Figure 1).

A complex dependency

From family members' points of view, once health care services had been contacted and the injury was being taken care of, "what followed", as written in one account (SPM) was the family's main concern. In an interview, a participant stated:

> [Our major problem was] the degree of dependency... how we were going to deal with it... Of course, it changes one's life it affects one's everyday life, in addition to the expectations as to what degree of dependency or autonomy she will have" (E5).

This dependence was not the result of an ageing process or the evolution of a chronic condition; it had "come about" as was commented on in a focus group (FG1). It was a new situation where the family had to deal with many "unexpected issues", that they felt they were not prepared for; to some the fall brought chaos (FG3; E1). The diminished and precarious health of the older relative, the caregiver's situation and family relations made the older person's dependency complex to manage (for further data illustrations see box 3).

For participants, the fall took place precisely because of their relative's increased weakness. In many instances the older relative had had previous falls that made them "weaker" and "afraid", as was stated in a focus group (FG3). It was also common that the older person had impaired functional ability and other ailments that interweaved and interacted with each other. For instance, a participant explained in an interview that the increased deafness of her father made it very difficult to manage his dependency after the fall (E2). Situations like these made things "even more difficult" (FG0) and "terribly complicated" (FG1) for caregivers. When the caregiver was also older, as in the

case of spousal caregivers, or had to care for more than one older relative as in the case of children caregivers with older parents, this situation became even more complex.

Finally, participants pointed to the difficulties they had in persuading their older relatives to take their advice in preventing future falls and in following suggested self-caring activities. Relations between spouses, parents and children could make things harder since the older person could resist their relative having more control over their life (E4; FG0). A participant in a focus group concluded "although we are adults, we are still children to her [mother] and she does not listen to us" (GF0).

To manage a complex dependency.

Family members managed the complex dependency generated by the fall by 1) obtaining the best conditions for discharge, 2) adjusting to the demands of the new situation and 3) making up for the shortcomings of the health care system (for data illustrations see box 3). Their aim was for their relative to gain the maximum autonomy.

1- *Obtaining the best conditions for discharge.*

The management of a relative's dependency begins before they leave the health care premises. Thus, they assess the situation on discharge and if they feel the conditions for discharge are not good, they work towards obtaining better conditions. This implies hard work for family members. During the study they gave accounts of seeking information and making contacts with physicians and other health care professionals, of challenging medical opinions and demanding their right to a service that they felt they needed and were entitled to (FG1; FG2; FG3; E5; E3). Also, relatives' contributions to creating the best conditions for discharge also involved "hands on" work. For example, while in hospital, the family helped their relative with activities that promoted their autonomy (E1; FG2). The family took every opportunity to get information about the health status of

their relative, care giving and the resources they might need for their relative's best recovery (FG0; FG1). Information was key for them to be prepared to cope with a complex situation.

The right time for discharge was a key issue for the family as the fall was entangled with issues that went beyond biomedical care. A participant commented:

> "Regarding *discharge, her leg was all right,* my mother could have left [hospital premises], *but she wasn't altogether well and* that was the decision that we [the family] had to make, that my mother was not [ready]...that we wanted her to stay [in hospital] a bit more". (E1. Emphasis added).

In other situations, the family needed the time to get organized and asked for a transfer to a long-term institution until they could make the necessary arrangements (E5). There were also instances where the family felt it necessary to have a referral to a given medical service, such as rehabilitation or neurology and they had to have confidence in their own judgement and demand a service that they felt was needed (E4; E3; FG2; FG3). For family members the older patient ought to be suitable for discharge and the discharge must have no loose ends and they themselves must be prepared to handle the situation.

2- Adjusting to the demands of the new situation.

With the relative's fall a time of crisis begins to compel family members to make changes in their lives, in their family relations and in the environment where the older relative lives (E1; E2; FG0; FG1). Even if the older person recovers autonomy, things in their lives are not going to be the same. The fear of another fall happening is in the family members' minds and they will continuously survey the situation for necessary adaptations and long-term care arrangements (E5; FG0).

The lives of those involved in caregiving change in an abrupt manner, they will lose autonomy together with their relative; a situation they need "to come to terms with it" (E2). Hence, during focus groups and interviews participants explained that to deal with their relative's complex dependency called for a reorganization of everyone's timetable to establish care shifts, it required coordinating caregiving activities and reaching family agreements for the well-being of the dependent relative (FG0, FG1; E4, E5).

Relationships with the older person also changed. Fostering the older person's autonomy and preventing a fall from occurring, demanded family members shifting to new roles such as those of command and control:

> I am now telling my mother all the time "mommy get the walker, walk up and down the corridor" otherwise she sits watching TV and knitting and I am constantly on at her.... I work at home and I am controlling her" (FG0)

The family also adapts the physical space where the older person lives to make it safe and more comfortable. For example, family members organize the building of ramps, they make adaptations in the bathroom and improve the lighting in the home; they introduce orthopaedic aids such as walking sticks and frames, buy special and comfortable armchairs for the relative's long periods of immobilization (FG0; FG1: FG3; E1; E5.) As the relatives' dependence evolves or improves, family members make the necessary adjustments.

Adjusting to deal with the complex dependency is therefore a multifaceted and continuous process. It requires continuous assessment by the family, family arrangements and surveillance of both, the older person and the place where he/she lives.

3- Meeting the shortcomings of the social and health care systems.

To manage the older person's complex dependency required many and varied resources that family members felt they needed but did not get from the health care system. Thus, during the study they gave numerous examples of how they supplied their own resources to make up for the shortcomings they encountered. For instance, they bought caregiving implements and mobility aids, hired home helps for the older person and paid for private services they felt the older relative needed (FG2; FG3). A participant commented:

> "...and we were paying a girl, a physiotherapist to come home because we noticed that... her legs are twisted, she has no muscular mass, she has little legs. And we thought, 'well maybe doing physiotherapy at least once a week at home..." (GF3).

The determination that their relative recovered their lost autonomy in the best conditions, prevailed over other considerations such as the availability of personal time and the economic cost. Not being entitled to resources or services did not deter family members from getting them if they deemed them to be necessary for their relatives' well-being. In this way family members created a net that caught what the social and health care systems did not.

But shortcomings were not always such; sometimes family members were unaware of what they were entitled to. This was highlighted in a focus group when a participant learned during the group discussion that she was entitled to home help (GF0). This lack of information hints at a situation that

overrides all the management strategies: being on their own without the necessary support, the main condition under which family members deal with the older relative's complex dependency and the final issue presented in this paper.

On their own and without the necessary support

Although participants in the study felt generally well treated by health professionals, they did not feel supported nor informed by them about how to handle their relative's complex dependency. The lack of information and support was a constant issue in participants' discussions; they felt abandoned by health care providers:

> "For what is being said [in the group] we can say that all professionals are very professional, that they know perfectly well how they must develop their work, but once they finish telling you everything, they turn their back or close the door, a total emptiness. And there you are, on your own..." (GF0).

Family members had to find information and solutions to contingencies on their own. During the study, they explained that they searched continuously for information among health professionals, relatives and friends; they learned by trial and error (GF3) and used their common sense to make up for the lack of practical information that "no one gives you" (GF2). Humbly they recognized that they "could do better" but that it was the best they could do, given their knowledge (FG3). In their pursuit to manage the complexity of their relative's dependence, they made mistakes which were acknowledged during the group discussions (FG0; FG3).

What the family missed the most was practical information about how to care for the dependent relative. The assertion "one only needs to know it" of a participant in a focus group (GF1) points to the fact that once this information is known, it is not so complicated to use it. Thus, learning to care for their relatives was a result of participants' efforts and of their own resources. In a focus group this was eloquently stated:

> "I think I speak for everyone when I say that this [caring for the elder relative] has been learning things the hard way; the hard way..." (GF1).

Family members learned to care for the dependent older relative and searched for the best solutions to manage the complex dependency with little or no professional orientation. In each situation, they did what they believed was good using their own initiative and to their best ability (FG3; E3). They solved simple things such as putting handgrips in a shower (GF3) and more complicated ones such as deciding when and under what conditions their older relatives could safely resume their normal lives (E4) on their own and without help; just like they decide which health specialist to select for a given treatment (GF3).

In their experience, the follow up after the fall was limited to that of the injury, while falls prevention was rarely mentioned and their needs disregarded (FG0; FG1; FG2; FG3; E3; E5). Caregivers were left to their own devices to care for the relative who had had a fall. Managing the complex dependency became a lonely job for them, where the presence of professionals' support was, in the best of cases, marginal.

DISCUSSION

This study has highlighted that a fall complicates the care of an older relative for the family. Preparing the transition to the home, adjusting and meeting the shortcomings of the health system revealed participant caregivers' capacity to deal with a highly complex situation and their key role in the care of a fragile older relative. Caregivers provide the best possible conditions for their relatives to regain the maximum autonomy and their activities also point to caregivers' crucial role in falls prevention, something that the literature is increasingly acknowledging (Greenwood, Mackenzie, Cloud & Wilson, 2009).

Falls generate dependency in older people (Roe et al., 2008). However, dependency tends to be presented in the bibliography as an umbrella term that covers many and varied situations but in an isolated manner. The complexity experienced by those who take care of fragile older people, as shown in this study, passes unnoticed.

Disturbingly, the present study shows that family caregivers care for their older relatives with little guidance from health professionals something that has been echoed in the literature (Gibson, Dickinson, Brittain & Robinson, 2015; Lee et al., 2013, Smith et al., 2004). It has been reported that during and after hospitalization, health professionals miss many opportunities to inform and educate patients and families about fall prevention (Lee et al., 2013). Studies have found that after a fall, hospital staff do not tend to refer older people to preventative interventions nor provide long-term guidance to prevent falls from happening again (Dickinson et al., 2011; Katz, 2011). After a fall, family caregivers report not receiving information about fall management and prevention from health professionals (Davey, Wiles, Ashburn & Murphy, 2004), information in the best cases, is "suboptimal" (Lee et al., 2013:14). The present study highlights how crucial this information is for caregivers giving the complexity of the task that they must accomplish following a fall.

Discharge is a key moment (Canary & Wilkins, 2017) and the participants of the study fully understood it. However, for caregivers', discharge is an unpleasant experience causing an emotional overload (Plank, Mazzoni & Cavada, 2012) with feelings of being unsupported and with a lack of resources to meet their needs and those of their sick relative (Canary & Wilkins 2017, Lee et al., 2013; Silva-Smith, 2007). In this way, the present study adds to those other studies that revealed the need the family has for information and help and their need for practical and psychological support at the time of their relative's discharge (Canary & Wilkins, 2017; Plank et al., 2012). In the case of a fall, this is of relevance since older people who have had a fall are at risk of having another fall with injury at home after discharge (Hill et al., 2011). The sense of isolation reported in the literature after discharge (Brereton & Nolan, 2002) together with the complexity of the older person's dependency uncovered in the present study, warns against continuing to overlook caregivers' needs for support and follow up after a fall.

Significant institutional changes and innovation have taken place in LTC policies across Europe. Most of the new programmes are based on a better integration of social care and health care together with the development of a social care arrangement based on a mix of family obligation, market provision and public support (Ranci & Pavolini, 2013). The care after a fall is a very sensitive juncture where all the different support provisions must meet. Preparedness for community-based care and discharge planning after a fall, falls into this new LTC policy calling for improved coordination between the LTC and health care sectors (Rostgaard, Timonen & Glendinnig, 2012).

Supporting caregivers is essential for the sustainability of long-term social and health care (Glendinning et al., 2009). Factors that contribute to the success of service and practice interventions are the tailoring of support to meet the needs of specific categories of caregivers and

acknowledging their specific concerns and care needs (Glendinning et al., 2009). By making visible the role played by caregivers following a fall, this study provides information to guide their effective support. For countries that rely on a family-based model of dependency, the findings of this study are especially relevant.

Limitations

Not all the family caregivers who were willing to participate in the focus groups could do so, precisely because they had to take care of a relative who had had a fall. With their participation, the data obtained could have been richer. The scarce support services provided by the Spanish welfare system have a bearing on the findings of this study. In places with better welfare services for dependent older people, it is likely that the feeling of being on their own felt by study participants would not be as harsh as in the present study. However, we believe in the merit of our research; it has shed light onto an issue overlooked in the literature.

CONCLUSION

The present study shows how families care for an older relative who has had a fall and shows how they achieve this with little guidance or support. Caregivers should not remain invisible to health services providers; otherwise their stress and burden could overwhelm them. Guides, protocols and information for the care of fragile older people, particularly after a fall, should include care and support to caregivers.

If health professionals are to be engaged in a collaborative process with older people's caregivers to prevent falls (Lampiasi & Jacobs, 2010), information and support must be intentional and strategic. Health professionals and especially nurses need to be aware and respond to family needs after a fall;

nurses must be proactive in preparing them to care for the older person. The discharge from health service premises of an older person who has had a fall must not be accompanied by feelings of abandonment and lack of care. Liaison nurses, the implementation of discharge protocols after a fall and the involvement of community health professionals are means to ensure this collaboration.

To the initiatives already in place for fall prevention, support must be added for family members to cope with the care of an older person following a fall. Public policies must accompany these initiatives; caregivers' need for support and information must not continue to go overlooked. It cannot be assumed that the family will continue to provide care for the fragile older person with a minimum of support. In the long run, unwillingness to invest in care giving could be costly (Glendinning et al., 2009).

Author Contributions:

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):

1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;

2) drafting the article or revising it critically for important intellectual content.

* http://www.icmje.org/recommendations/

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Box 1

Guide for the written accounts

As you know our study focuses on elderly people who have had a fall. Specifically, we would like to know your experience with health care services after (name of elder relative's) fall.

We invite you to tell us in writing about this experience. It will help us to know more about, and better understand the care provided after the fall of an elderly person. It will enable you to express yourself freely about your experience.

To do this, you might think about the care that you and your relative received:

- At the health centre/institution where your relative was taken
- When your relative left the health centre/institution
- At home: the care you received from health services or other support you got related to your relative's fall.

Be as descriptive and specific as you can. You might think you are writing a letter to a friend telling him/her about your experience.

Do not worry about grammar or style; we are just interested in learning about your experience.

We will read your account with respect and we will handle the information confidentially. We guarantee your anonymity.

Many thanks for your help and time.

Box 2-Focus group and interviews guide.

1) Ice breaker question: Could you please tell us something about you and about the person you care for?

2) After the fall. What can you tell us about the experience with health services just after your relative's fall?
   a. What happened?
   b. Probe question to stimulate discussion (based on analysis) and member check: People who had a similar experience have commented that… (include issue after analysis)
   i. What do you think?
   ii. How was your case?

3) On discharge. Let's discuss discharge from health premises (hospital or health center).
   a. What happened?
   b. Probe question to stimulate discussion (based on analysis) and member check: People who had a similar experience have commented that… (include issue after analysis)
   i. What do you think?
   ii. How was your case?

4) At home. Now you are at home, what is your experience with health care services?
   a. How did they contact with you?
   b. Probe question to stimulate discussion (based on analysis) and member check: People who had a similar experience have commented that… (include issue after analysis)
   i. What do you think?
   ii. How was your case?

5) If you could speak to the person in charge, what would you say?

Box 3 Data Illustrations-Main Categories

A complex dependency:

-"From this moment [after the fall] she becomes another person….her mobility is tremendously reduced, at this point she only goes from the arm chair in the sitting room, to the bath room and back with her walking frame, but she gets very tired" (FG0).

-"….my mother has many problems, my mother has a valve, my mother has a very bad knee, my mother has arthritis, and she has osteoporosis and many complications ...." (GF1).

-"…And now we are on this, from not having [her mother] ailments to now having a full schedule of doctors. Now each time we [children] have to get her to a medical consultation we have to call for health transport" (FG0).

-"Participant 1: "Then she is alone at home, she takes whatever is convenient for her, does whatever is convenient for her, because, well, although we can phone her and ask 'mom have you taken your pills?' and she says yes, then I check the pill box and see that the pills are there or to see that she has thrown them away"

Participant 3: [We have] to control. She leaves the crutch aside, she leaves the walking frame aside and then she wants to do the same things that she has done all her life, and when she realizes [that she cannot do them] she has no support and at that moment I might not be [around] and she falls, they [elderly people in this situation] fall.

Participant 2: It is the same thing, we come back to the same thing, they want to do what they have always done and now they cannot" (GF1).

To manage a complex situation:

-".... we [children] have tried to solve things along because the situation is highly complicated because my mother is now fully dependent" (E1).

-"Of course we tried to facilitate everything for her because she is not moving, she is very much afraid, she has accommodated herself and we know we are dealing with a person who was very active, that always went out in the morning, in afternoon and was very able and did not stop at home and now, well, she is completely the contrary" (FG0).

- "Then this is the leg and this [doctor] of the leg will tell us 'she must come in x days', for the follow up of the leg. Then we have the follow up with the endocrinologist, for the issue of the hypophysis she has, only the follow up of this. And then the Alzheimer, it also has a follow up" (FG03).

Obtaining the best conditions for discharge:

-“And on discharge I told her [a health professional] ‘I am not moving from here until you give me the information we [the family] came to get‘ and of course, there are different departments. So, I had to do something myself, I had to go to the department of patient care [complaints department] as things were not right” (FG0).

-The second time [she had a fall] she declined profoundly, and they told us [on discharge] that she did not need physiotherapy and we insisted ‘how come she does not need physiotherapy, she cannot walk’…from the first moment they told us that she did not need it and of course we insisted” (FG03).

Adjusting to the demands of the new situation

-“It was very difficult because she could not use a crutch, she could not use a walking frame, it was difficult for her to keep the balance…we are five brothers and sisters…we all live very close to each other and we organize well in shifts, in a friendly way” (FG0).

-“She is on a wheel chair, we have bought a comfortable and flexible arm chair, so she can move while seated; we have bought her casual and comfortable clothing, trousers, we are trying to make her as comfortable as possible and in fact we can see it... she appears to be now more tranquil” (GF1).

Meeting the shortcomings of the social and health care systems:

-“Yes, you have to rehabilitate her [the elderly relative] on your own, finding your own means, that is… (E3)”.

-“[My wife] as a matter of fact is depressed and is being treated by a private neurologist because, in the public system, they did not give us any solution” (GF2).

-“The situation is that she had a surgery and she left hospital worse because she could not and cannot walk anymore, the case is that she did not have any rehabilitation therapies, they told her that she does not need it. She is in a wheel chair…we are paying a physiotherapist to come home because we see that she is twisting and deforming herself completely” (FG03).

On their own and without the necessary support:

-“Researcher: And who told you this?

Participant: No one, we have inferred it. My sister said to me: ‘I will go to XXXX [a shop for dependency aids] and there they have everything, and they will tell me’. And off she went and kept buying what she thought was needed” (E5).

-“And we have done it, so that at least she [the elderly relative] can have a better quality of life, this is what we are trying to achieve in spite of the [circumstances]… we could do it better, but to my knowledge, that was the best we could do” (GF3).

-“Researcher: what do you mean by getting ‘small things’ like these?

Participant 1: Well, an indication of…

Participant 2: The procedures we have to follow.

Participant 3: Basic procedures but necessary, basic.

Participant 4: For me, in what order we have to do the wash. How we start to wash him. I learnt that we do the wash in an order… that it has an order and it has its logic, but you learn it by watching [at the auxiliary nurse] but no one teaches you”. (FG02)

Table1. Socio-demographic characteristics of participants (n=22)

Type of data collection	**Focal groups**				**Interviews**
	FG 0 (n=5)	**FG1 (n=5)**	**FG 2 (n=4)**	**FG 3 (n=3)**	**E1 E2 E3 E4 E5**
Sex	Female:1 Male: 4	Female:3 Male: 2	Female:1 Male: 3	Female:1 Male: 2	Female: 4 Male: 1
Age range in years	54-73	32-68	53-71	52-63	51-59
Education	Higher education:5	Primary School: 2 Secondary school: 2 Not formal:1	Higher education: 3 Further educación: 1	Secondary school:1 Further education: 2	Higher education: 3 Secondary school: 1 Further education:1
Relation to care	Spouse:1 Offspring:4	Spouse: 2 Offspring: 2 Grandchild: 1	Spouse: 3 Offspring: 1	Offspring: 2 Sibling:1	Offspring: 5

Length of time providing care	8 months to 8+ years	1 year to 20+years	4 months to 5 years	3 years to 10+ years	1 months to 20 years
Living Arrangement	Co-reside: 3 No co-reside: 2	Co-reside: 3 No co-reside: 2	Co-reside: 3 No co-reside: 1	Co-reside: 2 No co-reside: 1	Co-reside: 2 No co-reside: 3

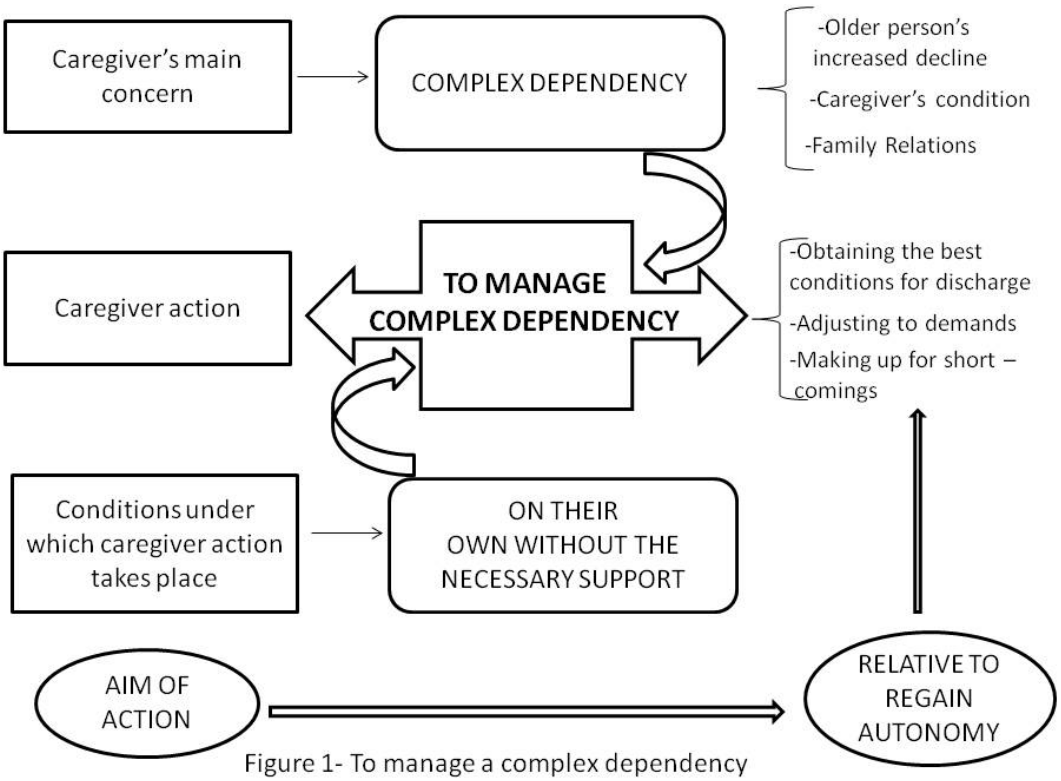

Figure 1- To manage a complex dependency